MIND OVER BLADDER:
WOMEN, AGING AND BLADDER HEALTH

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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctorate in Nursing Practice in the department of the School of Nursing.

Chapel Hill
2017

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ABSTRACT

Joanna Elizabeth Long: Mind Over Bladder: Aging, Women and Bladder Health
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Objectives: The purpose of this study was to explore the efficacy and feasibility of an innovative, electronically delivered self-management intervention that included daily mindfulness practice, completion of sequential bladder diaries and bladder health education to improve urinary incontinence in older women who lived independently in a retirement community.

Methods: This study was a mixed methods pilot study over eight weeks with ten women. The intervention was delivered via a custom made website (http://mindoverbladder-chaicore.vipapps.unc.edu) and included reviewing bladder health education, completion of a 3-day bladder diary at Intervention weeks 1, 5 and 8, and 2 weeks of guided mindfulness practice followed by 6 weeks of mindfulness practice of the participants' choice.

Results: Eight women completed the study. One woman's data were excluded due to no incontinent episodes at baseline. Five of seven (71%) women had a decrease in daily urinary leakage episodes. A statistically significant decrease ($p= 0.041$) was found between pre and post scores (with 0 = not at all to 10 = a great deal) on the item, "how much does urinary incontinence affect your everyday life?" Seventy-one percent (N=5) of women reported subjective improvement in incontinence. High scores were found on the feasibility survey and all women said they would recommend the study to other women who have urinary incontinence.

Conclusions: The self-management intervention was effective for the participants in improving health related quality of life associated with urinary incontinence and perceived self-efficacy to manage urinary incontinence. The electronically delivered intervention was feasible in the sample population. Improvements should be made in volume control and motivational tools, and developing a website or mobile application that will allow public access. Further research is needed in a larger and diverse population of older women.

TABLE OF CONTENTS

LIST OF TABLES……..…vii

LIST OF FIGURES……..……..viii

LIST OF ABBREVIATIONS…….…….....ix

CHAPTER 1: IMPROVING CARE FOR OLDER WOMEN WITH URINARY INCONTINENCE…....1

Introduction…….…….…1

Background and Significance……...2

Purpose of Project and Clinical/Practice Question……...……...4

CHAPTER 2: THE EVIDENCE BASE FOR SELF-MANAGEMENT STRATEGIES AND MINDFULNESS IN URINARY INCONTINENCE MANAGEMENT……...…….…….....5

Introduction: A Review of the Literature…….…….5

The Burden of Urinary Incontinence……5

Self Management Strategies for Urinary Incontinence and the Case for Mindfulness…….…6

Improving the Adoption of Self-Management Strategies for Urinary Incontinence……..10

CHAPTER 3: CONCEPTUAL AND THEORETICAL FRAMEWORK…….…….…….12

Complexity Science……...……12

Social Cognitive Theory…….……13

CHAPTER 4: ORGANIZATION OF THE DNP PROJECT…….……16

Project Design Overview……...……16

Methodology……...17

Procedure Overview……21

CHAPTER 5: DATA ANALYSIS…….……...……..25

Results…….……..…….…….25

Discussion…….36

CHAPTER 6: FUTURE CLINICAL AND RESEARCH IMPLICATIONS AND RECOMMENDATIONS…….....41

Clinical Practice Implications and Recommendations……..……..41

Research Implications and Recommendations…….....…….43

CHAPTER 7: SUMMARY…….……44

Conclusion…….....44

APPENDIX A: SCREEN SHOTS FROM THE MIND OVER BLADDER WEBSITE……45

APPENDIX B: PRIMARY DATA COLLECTION QUESTIONNAIRE…….....47

APPENDIX C: GERIATRIC SELF-EFFICACY SCALE FOR URINARY INCONTINENCE……...…55

APPENDIX D: PERMISSIONS TO USE QUESTIONNAIRES AND SCALES……..56

APPENDIX E: POST-STUDY FEASIBILITY QUESTIONNAIRE……59

APPENDIX F: QUESTIONS TO GUIDE THE SEMI-STRUCTURED INTERVIEW……60

APPENDIX G: PROJECT TIMELINE……...……61

REFERENCES…….62

LIST OF TABLES

Table

1. Characteristics of Study Participants.……..……...…….…...26

2. Mindfulness Completion for Each Participant…….……..27

3. Bladder-related Outcomes Pertaining to Research Question One....……...…..29

4. Post-intervention Feasibility Survey Results ……..……..34

LIST OF FIGURES

Figure 1 – Baseline and Post-Intervention Three-day Daily Average Number of Voids…..…...30

Figure 2 – Baseline and Post-Intervention Three-day Daily Average Number of Incontinent Episodes…….30

Figure 3 – Baseline and Post-Intervention Geriatric Self Efficacy Scale for Urinary Incontinence Total Scores……...…….....31

Figure 4 –ICIQ-FLUTS Quantitative Scores of Bother…….....……..32

LIST OF ABBREVIATIONS

AUA	American Urologic Association
GSE-UI	Geriatric Self-Efficacy Scale for Urinary Incontinence
ICS	International Continence Society
ICS-FLUTS	International Consultation on Incontinence –Female Lower Urinary Tract Symptoms
TB-WEB	Women's Toileting Behavior's Scale

CHAPTER 1:

IMPROVING CARE FOR OLDER WOMEN WITH URINARY INCONTINENCE

Introduction

Despite the high prevalence of urinary incontinence in older women, the significant costs of its management and treatment, and its impact on quality of life, older women often do not receive timely and effective care. Urinary incontinence affects an estimated 26% of women, with higher estimates of 37% in women 65 and older (Hawkins et al., 2011; Baker, Costa & Nygaard, 2012). By 2020, in the United States, the healthcare system and affected individuals will spend more than USD 82 billion on the treatment of urinary incontinence (Coyne et al., 2014). Additionally, urinary incontinence is linked to significant medical, psychological, and social distress and has a stronger influence on quality of life than diabetes, cancer, and arthritis (Hawkins et al., 2011). Despite such significant personal and socioeconomic burden, urinary incontinence is under-recognized and undertreated by clinicians; in fact, less than 25% of women with urinary incontinence feel that it is adequately addressed. (Hawkins et al., 2011; Tannenbaum, Mayo & Duchare, 2005).

Urgency urinary incontinence, compared to stress urinary incontinence, is found to particularly decrease quality of life related to incontinence (Riss, 2011). This project will specifically address urgency urinary incontinence. The term urinary incontinence used throughout this document refers to urgency urinary incontinence. The International Continence Society (ICS) definition for urgency urinary incontinence is "the complaint of involuntary loss of urine associated with urgency" (Hayden et al., 2010). In contrast, female stress urinary

incontinence is “the complaint of involuntary loss of urine on effort or physical exertion (e.g. sporting activities) or on sneezing or coughing” (Hayden et al., 2010). Mixed urinary incontinence is “the complaint of involuntary loss of urine associated with urgency and also with effort or physical exertion or on sneezing or coughing” (Hayden et al., 2010). This project may also be effective for urgency urinary incontinence in women with mixed urinary incontinence, not just urgency urinary incontinence alone.

Background and Significance

Professional association recommendations support the use of effective non-pharmacologic self-management treatments of urinary incontinence as first-line therapies (AUA, 2014). Both novel and long-established evidenced-based self-management strategies to address urinary incontinence are available, including pelvic floor muscle exercises, biofeedback and timed voiding (AUA, 2014). Continence promotion, which includes education regarding therapeutic and non-therapeutic behaviors for women to engage in to improve bothersome symptoms, and the use of a bladder diary are long-standing effective components of self-management strategies (AUA, 2014). The bladder diary is effective in helping to diagnose lower urinary tract symptoms and focusing affected women’s attention and that of their care providers on the presence of symptoms, current bladder habits, and possible triggers for incontinence (AUA, 2014).

In recent years the understanding of the brain-bladder connection has evolved. The pathophysiology of urinary incontinence has become better understood to be, in part, a functional disorder, secondary to cognitive dysfunction rather than exclusively a neurogenic or organ dysfunction. Mindfulness is being recognized as a promising self-management tool that addresses the brain-bladder connection. Mindfulness practice is a novel, non-pharmacologic

strategy that has been shown to significantly reduce prevalence of urinary incontinence episodes in women and subsequently improve quality of life related to urinary incontinence (Baker, Costa, Guarino & Nygaard, 2014). Mindfulness strategies are rooted in the work of Jon Kabat-Zinn who developed Mindfulness Based Stress Reduction therapy in the 1970s to address psychological stress in certain populations (Kabat-Zinn, 2005). Mindfulness involves a person paying purposeful attention in the present moment without judgment or reactivity (Kabat-Zinn, 2005). Mindfulness can be done formally, such as through meditation, or informally, such as being mindful while eating or walking. Mindfulness practice addresses the cognitive dysfunction, or brain-bladder connection, by its focus on changing the cognitive response to bladder filling and sensations of urgency that previous incontinence therapies have not.

Despite availability of self-management strategies and recommendations to use them, these therapies are often not encouraged by healthcare providers, and as a consequence many women suffer from urinary incontinence and its side effects. One reason that self-management interventions such as use of the bladder diary and mindfulness practice may not be frequently used by clinicians is the time intensity to teach, perform, and evaluate them. Thus, these interventions can be difficult to embed into non-specialty clinical practice by health care providers (Demarzo, Cebolla & Garcia-Campayo, 2015). Reducing the labor-intensity of teaching and monitoring self-management practices could be achieved through the use of electronic delivery, such as a website or CD, of a self-management intervention that incorporates mindfulness practice, continence promotion education, and a bladder diary.

Purpose of Project and Research Questions

A pilot project that incorporates these evidence based bladder management strategies into a community setting through web-based or multimedia delivery was established to address this

gap in clinical management of older women with urinary incontinence. The project included development, implementation, and evaluation of an electronically delivered, via website or CD, self-management intervention for urinary incontinence in older women living independently in a retirement community. The purpose of the project was to investigate the efficacy of the intervention on improving health related quality of life for community-dwelling older women who have urinary incontinence. The findings from the project will guide practice improvement recommendations for widespread adoption of this self-management intervention for women with urinary incontinence. The findings may also benefit health care providers by affording them an effective and easy to implement intervention and as a consequence improve urinary incontinence treatment for older women in the community setting.

The project addressed two research questions: 1) Is a multi-component electronically-delivered self-management intervention effective in improving health related quality of life associated with urinary incontinence in older women who live independently in a retirement community? *and,* 2) Is the intervention feasible for use in older adult women who live independently in a retirement community?

CHAPTER 2:

THE EVIDENCE BASE FOR SELF-MANAGEMENT STRATEGIES AND MINDFULNESS IN URINARY INCONTINENCE MANAGEMENT

Introduction: A Review of the Literature

The literature reviews comprised searches of the CINAHL and Pubmed databases and also included references identified from pertinent published studies. The search was limited to English only articles and publication dates within the past ten years when the search was initiated (i.e., 2005-2015). Search terms included "urinary incontinence (UI) and mindfulness," "urinary and mindfulness," "mindfulness and self-management," "UI and self-management," "overactive bladder and mindfulness," "overactive bladder and self-management," "bladder diary," and "self-efficacy and UI." Filters for the search included women and individuals greater than 65.

The Burden of Urinary Incontinence

Urinary incontinence is associated with significantly decreased health related quality of life, even more so than cardiovascular disease and diabetes (Hawkins et al., 2011; Coyne et al., 2013). Greater impairment of health related quality of life has been associated with increased severity or frequency of urinary incontinence symptoms (Choi, Lam & Chin, 2014; Riss & Kargl, 2011). It is associated with falls, anxiety, depression, urinary tract infection, increased body mass index, diabetes; and it also affects sexual function and work productivity (Coyne et al., 2013; Molinuevo & Batista-Miranda, 2012; Osman & Chapple, 2013). Studies that evaluated urinary incontinence's effects on major depressive disorder found that urinary incontinence

increases the risk of major depressive disorder and, when the two co-occur, major depressive disorder cannot be adequately treated without successfully addressing urinary incontinence (White, Reeve, Chen, Stover & Irwin, 2014). Occupational medicine has investigated the cost of urinary incontinence in the work place and societal costs have also been evaluated. A staggering USD 82 billion is expected to be spent on management of urinary incontinence by 2020 by affected individuals and the healthcare system in the United States (Coyne et al., 2014). Employees with urinary incontinence had greater than two times as many medical and pharmacologic costs and greater absenteeism (Kleinman, Chieh, Atkinson, Odell & Zou, 2014). It is possible that improved diagnosis and management of urinary incontinence may lead to significant economic and psychosocial benefits.

Self-Management Strategies for Urinary Incontinence and the Case for Mindfulness

Multiple reviewed literature revealed that despite urinary incontinence's significant personal and socioeconomic burden, it is under-recognized and under treated in the community setting. Women have conveyed frustration with the level of information about urinary incontinence and its management (Siddiqui, Ammarell, Wu, Sandoval & Bosworth, 2016). One explanation for under-treatment of urinary incontinence is the stigma attached to it. Sociological research has shown urinary incontinence to be "taboo," preventing help-seeking behaviors by those affected (Bjork, Sjostrom, Johansson, Samuelsson & Umefjord, 2014; Hoogsteyns & Van, 2015). Self-management strategies can provide a solution to this challenge in addressing urinary incontinence. Self-management strategies can lead to significant improvement in urinary incontinence, while addressing embarrassment associated with it because these strategies promote patient autonomy and uphold women's privacy (Bjork et al, 2014). Further, self-management strategies provide empowerment for women by providing a sense of control (Bjork

et al, 2014; Hoogsteyns & Van, 2015). Normalizing help-seeking behaviors and improving self-efficacy about managing urinary incontinence can help preserve self-esteem and empower women (Bjork et al, 2014; Hoogsteyns & Van, 2015).

A second explanation for inadequate and ineffective treatment of urinary incontinence is that despite guidelines recommending behavioral therapies as first-line treatment for incontinence (AUA, 2014), medications are often the first or only therapy offered by healthcare providers. These medications can have significant adverse effects which in turn decreases adherence and patient satisfaction with therapies (Baker et al., 2014). Pharmacologic and surgical interventions should be second and third line therapies after behavioral and self-management strategies have been employed and evaluated (Ellsworth, 2014; Holroyd-Leduc et al., 2011). Evidence exists that behavioral strategies improve urinary incontinence as much as or more than pharmacologic therapies, and they have no adverse effects and are recommended in many evidence-based guidelines as first-line treatment for urinary incontinence (AUA, 2014; Vaughn et al., 2011). Further, because complete cure is often difficult to attain, a patient-centered, symptom management approach that increases self-efficacy to manage incontinence is essential for effective treatment (Anger et al., 2011; Riss, 2011; Kelly, Marie & Jordan, 2015).

The bladder diary and mindfulness as self-management strategies. Psychological studies of urinary incontinence suggest that emotional, cognitive and behavioral responses should all be considered when treating patients with urinary incontinence (Molinuevo, Batista-Miranda, 2012). Mindfulness and a bladder diary address each of these responses and can be incorporated into a patient centered self-management strategy (Berke, 2012; Baker et al., 2014). The bladder diary has long been supported as a cornerstone of urinary incontinence management (Berke, 2012; AUA, 2014). It can serve as a diagnostic tool, but also provides important self-

awareness of modifiable choices that contribute to urinary incontinence (Berke, 2012; Jimenez-Cidre, 2015; Hikita et al, 2015). Self-awareness is a powerful self-management tool; for example, food diaries are cornerstones of weight-loss interventions because they make an individual aware of her behaviors and choices and how these affect weight gain or loss. Similarly, the bladder diary provides useful information for individuals trying to manage their bladder. The bladder diary has been validated as a tool for evaluating urinary incontinence symptoms and is considered the gold standard (Salvatore, 2014). While the bladder diary has long been established as a cornerstone of urinary incontinence care, mindfulness is a promising, novel self-management tool as a way to address the brain-bladder connection.

Mindfulness has been shown to improve self-care and self-management of chronic, functional conditions, including irritable bowel syndrome, fibromyalgia, headache, chronic pain and chronic obstructive pulmonary disease, and in recent years has been shown to decrease urinary incontinence episodes (Baker et al., 2012; Bawa et al., 2015; Benzo, 2013; Day et al., 2014; Matchim, Armer & Stuart, 2008). In studies that evaluated mindfulness' effects on urinary incontinence, mindfulness was shown to be more effective than yoga therapy and at least as effective as routine pharmacologic therapies and bladder training. Specifically, mindfulness was found to significantly decrease daily incontinence episodes from 4.14 to 1.23 (P= 0.0005) (Baker et al., 2012), and mindfulness' outcome of improved health related quality of life was statistically significant compared to yoga therapy (Baker, Costa & Nygaard, 2012; Baker et al., 2014).

Proposed mechanism of action for mindfulness. The brain-body connection is thought to be the reason for mindfulness' therapeutic effects (Bawa et al., 2015; Benzo, 2013; Day et al., 2014; Matchim et al., 2008). Imaging studies provide improved understanding of the role that

mindfulness plays in addressing the brain-bladder connection. Functional MRIs of women with overactive bladder have shown exaggerated activation in the emotional cortex of the brain when a woman is experiencing strong sensations of bladder fullness, indicating a strong reaction to the perceived threat of an incontinent episode (Baker et al., 2012; Tadic et al., 2012). The heightened emotional response increases cognitive perception of the afferent nerves in the bladder, resulting in perceptions of bladder fullness that exceed the threshold for voluntary control, resulting in involuntary leakage (Tadic et al., 2012). Additionally, increased sensitivity to bladder sensation biases perception of symptoms, such as exaggerated urgency, which can decrease perceived ability to self-manage incontinence (Molineuvo & Batista-Miranda, 2012).

Similar findings of mindfulness' effects on the brain-body connection have been demonstrated through studies evaluating interventions for irritable bowel syndrome. Garland et al. (2012) studied the effectiveness of mindfulness training to address irritable bowel syndrome and found that mindfulness training was significantly therapeutic on irritable bowel syndrome severity and quality of life. The authors postulated that non-reactivity to anxiety provoked by sensations in the gut and reduction of catastrophizing linked to emotional interference led to the therapeutic effects (Garland et al., 2012). As with irritable bowel syndrome, emotional arousal plays a role in urinary incontinence management, and mindfulness may be a valuable tool to address this.

Studies have demonstrated neuroplasticity of the brain in response to brain-bladder interventions, such as mindfulness, which suggest that the brain can learn to more appropriately perceive bladder fullness (Baker et al., 2012). Mindfulness takes advantage of the neuroplasticity of the brain by allowing for down-regulation of the strong emotional component

linked to bladder fullness, thus changing a woman's perception of bladder fullness and her perceived ability to control her bladder (Baker et al., 2012).

Improving the Adoption of Self-Management Strategies

Mindfulness, paired with bladder diaries and brief bladder health education, has potential to be a powerful, holistic self-management strategy to address the physical, psychological and social aspects of urinary incontinence; however, a noted barrier to prescribing these self-management strategies by healthcare providers in community settings are that they are time and labor intensive, making them difficult to incorporate into practice (Andrade, Anam, Karanam, Downey & Ruiz, 2015; Huang, Jenny, Chesney Schembri & Subak, 2014). By reducing the labor-intensive nature of self-management, a significant barrier to widespread adoption of this intervention will be eliminated (Andrade et al, 2015; Ruiz et al, 2011).

Several studies have evaluated the efficacy of online self-management interventions for urinary incontinence and have found that they are feasible and effective in improving urinary incontinence (Andrade et al., 2015; Barbato, Weibe, Cline & Hellier, 2014; Ruiz et al., 2011). Online and multimedia interventions are especially effective in increasing older adults' confidence in coping with and managing urinary incontinence and overactive bladder (Andrade et al., 2015; Ruiz et al., 2011). A study by Ruiz et al. (2011) reviewed the use of self-management interventions in women over 55 with overactive bladder. In this study internet based programs utilized multimedia e-learning tools, social networking features and online resources over a 6-week period, and significant improvements in continence management were realized for this specific population group (Ruiz et al., 2011). A study of stress urinary incontinence showed overwhelming support by participants for online self-management programs to improve symptoms of stress urinary incontinence in middle-aged females,

suggesting that similar interventions could be tailored to urgency urinary incontinence in older adult women and provide significant symptom improvement (Barbato et al., 2014). Additionally, by fostering easy accessibility, multimedia and web-based interventions have been found to lower the barrier for women to seek care for urinary incontinence, a noted reason for urinary incontinence's inadequate treatment in community settings (Bjork, 2014). For example, online care forums and discussion boards provide venues to provide support for women with urinary incontinence, while providing privacy and respecting individuals' autonomy. Thus this modality addresses sociologic aspects of urinary incontinence that may impede seeking care (Hoogsteyns & Van, 2015).

The literature reviewed for this project revealed support for using mindfulness and a bladder diary as self-management strategies for urinary incontinence in older women. Additionally, online and multimedia modalities have been proven effective in providing urinary incontinence interventions. To address the current inadequate and ineffective treatment of women with urinary incontinence, this project will combine the use of evidence-based self-management strategies and electronic delivery modalities in order to improve care of older women with urinary incontinence in the community setting.

CHAPTER 3

CONCEPTUAL AND THEORETICAL FRAMEWORKS

Complexity Science

Complexity science is emerging as a way to understand complex adaptive systems, such as the human body, and provides a lens to better understand bladder control, especially the brain-bladder connection. Complexity science asserts that the human body is a complex system made up of dynamic, interacting, and interconnecting parts that affect one another (Engebretson & Hickey, 2015). Complexity science suggests that reductionist principles that traditionally governed scientific inquiry are not sufficient to understand complex adaptive systems, and it offers a feasible explanation for why urinary incontinence in older women is currently inadequately treated. Reductionist principles restrict understanding to simple cause and effect mechanisms with a focus on one body part or component of a whole (Engebretson & Hickey, 2015). Traditionally reductionist principles have guided research and clinical practice for older women with urinary incontinence. Reliance of pharmacologic interventions that address only neurogenic and muscular causes of urinary incontinence are guided by reductionist thinking and do not recognize the body as a complex adaptive system nor do they address the relationships between the cognitive, emotive, environmental domains and bladder structures that contribute to urinary incontinence (Baker et al., 2014; Engebretson & Hickey, 2015; Molineuvo & Batista-Miranda, 2011). Complexity science, therefore, recognizes relationships between the bladder

and emotion and cognitive structures that traditional reductionist thinking did not, serving as a foundation to better understand the brain-bladder connection.

Social Cognitive Theory

While complexity science offers a framework for understanding the brain-bladder connection, social cognitive theory, developed by Albert Bandura, provides a framework to guide the study (Bandura, 1977). One aspect of the social cognitive theory that makes it particularly useful to this project is the psychological, or mind-body, emphasis. A key difference to this study, compared to many others that address urinary incontinence, is that in this study urinary incontinence is viewed as a behavior susceptible to management rather than a pathology that cannot be controlled. The brain-bladder connection allows urinary incontinence to be seen as a cognitively mediated behavior, not simply a neurogenic or myogenic dysfunction. Further, evidence suggests that psychological factors play an important role in urinary incontinence. Placebo has been shown to decrease incontinence between 32 and 65% (Tannenbaum et al., 2008). The placebo effect could be related to behavior as people become aware of their own voiding habits and factors that increase the risk of urinary incontinence. Another possible cause for the placebo effect could be improved self-efficacy for retaining urine under voluntary control (Tannenbaum et al., 2008). Promoting self-efficacy for managing incontinence is central to this study, thus social cognitive theory's focus on improving one's self-efficacy makes it a useful framework for this study. The social cognitive theory has been used to guide many self-management interventions to increase self-efficacy, including smoking cessation, weight loss and increased physical activity (Glanz, Burke & Rimmer, 2015). Social cognitive theory provides a valuable framework to address the mind-body connection by restructuring learned cognitive patterns into healthier patterns, especially through enhancing self-efficacy.

Social cognitive theory lays a framework for how self-efficacy is developed. Social cognitive theory utilizes perceived self-efficacy as a predictor for one's ability to carry out a specified behavior (Bandura, 1977; Bandura 2012). Bandura asserts that self-efficacy comes from four primary sources: performance accomplishments, vicarious experience, verbal persuasion, and emotional arousal (Bandura, 1977; Bandura, 2012). Previous personal experiences with these four sources affects self-efficacy and providing interventions aimed at these sources in combination can affect future perceived self-efficacy (Bandura, 1977). This intervention addressed each of these four primary sources in order to increase self-efficacy.

Emotional arousal is one primary source for self-efficacy. Bandura (1977) asserts that high emotional arousal debilitates successful performance and that a woman is most likely to perceive high self-efficacy when she is not tense or agitated. In this pilot study, emotional arousal was addressed through mindfulness training. Mindfulness fosters neuroplasticity of the brain that allows for down-regulation of the strong emotional component linked to bladder fullness (Baker et al., 2012). Mindfulness can address heightened emotional arousal linked to overactive bladder, which in turn may improve perceived self-efficacy (Molineuvo & Batista-Miranda, 2012).

A second source of self-efficacy, verbal persuasion, comes from printed and multimedia bladder health education and mindfulness instruction videos. According to Bandura, verbal persuasion, through suggestion from outside sources, encourages one's belief that she can cope with what has overwhelmed her in the past (Bandura, 1977). The website created for the project includes written and video instruction regarding continence promotion and also discusses quality of life improvement secondary to mindfulness. Self-management of urinary incontinence was encouraged through the study, rather than the women taking steps to normalize urinary

incontinence as a part of aging and as such perceiving urinary incontinence as a condition that cannot be helped. Through written word and video, this intervention aimed to persuade women that urinary incontinence is not a normal part of aging and that self-management can be effective for urinary incontinence.

The third primary source, vicarious experience, occurs through shared experience. Vicarious experience can increase self-efficacy through observation of others performing behaviors successfully (Bandura, 1977). Due to privacy concerns, women did not meet in groups during the study, but women were encouraged to discuss urinary incontinence with their health care providers and other individuals who might be struggling with incontinence as well. These shared experiences can allow women to learn from their health care providers and others of ways to better manage their incontinence.

A final and fourth source of self-efficacy, performance accomplishments, was addressed through the bladder diary. Performance accomplishments are successes that create personal mastery of a behavior (Bandura, 1977). Successes increase personal mastery and failures decrease personal mastery (Bandura, 1977). The bladder diary allowed women to monitor continence performance and for accomplishments to be recognized. For example, as continent behaviors were tracked, improvement was monitored and improvement can strengthen the individual's sense of self-efficacy in controlling bladder habits.

CHAPTER 4

ORGANIZATION OF THE DNP PROJECT

Project Design Overview

This was a mixed methods pilot study that analyzed pre and post-intervention quantitative data and post-intervention qualitative data to assess effectiveness and feasibility of the web-based intervention with older adult women who lived independently in a retirement community and self-reported urinary incontinence. A website, Mind Over Bladder (http://mindoverbladder-chaicore.vipapps.unc.edu), was created and used to deliver the 8- week intervention. The website includes brief bladder health education, guidance for mindfulness practice, and access to a three-day bladder diary. For women unable to use the website, a CD was provided to guide the mindfulness practice and written bladder health information and hard copy bladder diaries were provided to each participant. The guided mindfulness practice provided through the CD was identical to that on the website. Electronic delivery of the intervention was chosen in order to ease access to the intervention and to allow flexibility for the women to complete the intervention in their own home and on their own time. Additionally, it would not require extra effort on the part of healthcare providers, which in turn may encourage adoption of this management program by providers.

The 8-week time period for the intervention phase was chosen as it is consistent with mindfulness-based stress reduction originally created by Dr. Kabat-Zinn, and this time frame was

used in previous studies that support the use of mindfulness to manage urinary incontinence (Baker et al, 2012; Baker et al., 2014).

Methodology

Participants. The study participants lived independently in a retirement community and volunteered to be part of the study. Participants were recruited through emails, mailed flyers, and announcements made in the community newsletter, on community bulletin boards, and in physical activity and enrichment classes. Participants who completed the study received a $15 gift card for the retirement community's gift shop. Convenience sampling was used, and the sample size was 10 participants, similar to that of previous pilot studies that utilize mindfulness based stress reduction (Baker et al., 2012). Inclusion criteria included women, age 65 and older, who self-identified as having urgency or mixed urinary incontinence, and who were able to speak, read and write English. Exclusion criteria included men, women under the age of 65, women who only experienced stress urinary incontinence, and women who had a cognitive impairment that prevented the ability to read and understand the instructions that guided the intervention. The Mini-Cog was used to screen interested participants for cognitive impairment at the first face to face meeting (Borson, Scanlan & Brush, 2000; Ebell, 2009).

Setting. The non-profit continuing care retirement community, located in a small city in the Piedmont region of North Carolina, was selected as the recruitment site as there is a large, concentrated population of women over the age of 65, and there is a robust enrichment program that encourages health promotion and actively encourages its residents to involve themselves in health improvement activities and behaviors. The life enrichment director at the retirement community facilitated access and recruitment to the participants. Having one site allowed for easier technical support to the participants throughout the intervention. The project was

completed by the individual participants in their own homes or preferred locations. No setting or location was specified to carry out the self-management intervention.

Website. The evidence-based website, Mind over Bladder, was developed to deliver the 8-week intervention. The website includes three primary components with subsections in each component. See Appendix A for screen shots of the website. Attention was paid to developing a user-friendly website appropriate for the target population. Content was written with regard to healthcare literacy. Plain-language was used. Website content was evidence-based and reviewed by an expert in the field of lower urinary tract symptoms and geriatrics.

The first component of the website was bladder health education. The content included were general anatomy and physiology of the bladder and definitions and terminology for common bladder problems. This section also provided a brief introduction to the brain-bladder connection. This content was derived from established professional organizations, including the American Urologic Association (AUA) and International Continence Society (ICS), and recent research in the field of urology.

The second component provided brief instruction on mindfulness, including what it is and how to pursue mindfulness practice, 14 days of specific guided mindfulness practices that could be directly accessed from the website, and a mindfulness-practice resource bank with links to find other guided mindfulness practice. The content of this section was grounded in Mindfulness-Based Stress Reduction developed by Dr. Kabat-Zinn and included an approximately 5-minute video of Dr. Kabat-Zinn explaining mindfulness.

The third component was a link to the ICS bladder diary; however, paper copies of this bladder diary were distributed to the women for use. The paper copy was given so that the bladder diaries could be collected after each one was completed for use in data collection and

analysis. The ICS bladder diary included recordings of daily voids, daily leaks, amount and type of fluid consumed and pad changes. The ICS bladder diary and instructions on how to complete it were available to the public on the ICS website as part of a bladder health awareness campaign.

Data collection tools and management. The primary data collection questionnaire (Appendix B) was a previously developed questionnaire (permission granted by Palmer, M.H, 2017) and assessed demographic information, presence of urinary incontinence through the International Consortium Incontinence Questionnaire-Female Lower Urinary Tract Symptom (ICIQ-FLUTS), and toileting behaviors through the TB-WEB and was used pre and post intervention. Additionally, the Geriatric Self-Efficacy Scale for Urinary Incontinence (GSE-UI) was used to collect data (Appendix C) (Tannenbaum et al., 2009). The two questionnaires were administered both pre and post intervention to assess impact and improvement of symptoms. Permission to use these tools was granted for use for this project (Appendix D). A feasibility questionnaire (Appendix E) and semi-structured interview script (Appendix F), developed for the study by the primary researcher, were used post-intervention to collect feasibility data and qualitative data pertaining to the women's experience with the study.

Primary data collection questionnaire. The baseline questionnaire included six demographic items, six health characteristic items, the ICIQ- FLUTS (ICIQ,2014), and the TB-WEB (Wang & Palmer, 2011; Palmer & Newman, 2015). Additionally, an item developed by the primary researcher was included regarding previous or current use of mindfulness.

ICIQ-FLUTS. This is a 12-item questionnaire that measures quality of life impact of lower urinary tract symptoms in women, including urinary incontinence. The ICIQ-FLUTS captures the wide range of lower urinary tract symptoms and can help to better understand

severity of symptoms and how specific lower urinary tract symptoms affect quality of life (ICIQ, 2014). Particular attention was paid to the questions that address the effects of urinary incontinence on quality of life.

TB-WEB. The TB-WEB is a 26-item tool that assesses women's toileting behaviors and has demonstrated reliability and validity (Wang & Palmer, 2011; Palmer, Wu, Rupp, Marquez & Newman, 2015). Toileting behaviors likely affect bladder health and can contribute to bladder dysfunction, thus when addressing bladder health, it is important to understand a woman's toileting behaviors (Wang & Palmer, 2011). This tool allowed for assessment of toileting behaviors older women use on a habitual basis (i.e. often/always) and may provide evidence that further bladder health education is needed in women who engage in behaviors that may negatively affect bladder health, and patterns may be ascertained to better understand the relationship between toileting behaviors and women's ability to self-manage incontinence.

Geriatric self-efficacy scale for urinary incontinence. The GSE-UI is a validated tool that measures the perceived self-efficacy of a person's ability to manage incontinence symptoms (Tannenbaum et al., 2009). The GSE-UI contains 12 questions that are answered on a Likert-scale of 0-10 with 0 being not confident and 10 being very confident. Total scores may range from 0-120.

Feasibility questionnaire and semi-structured interview. A post-intervention pen and paper Likert-scale questionnaire was completed at the final one-on-one meeting to capture the feasibility of the intervention and to assess the participant's perceptions about the intervention. Additionally, qualitative data were captured from the semi-structured individual interviews at the final meeting. These data were transcribed and analyzed for themes and patterns.

Data Management. Quantitative data obtained from the validated questionnaires were entered into a Microsoft Excel spreadsheet. Care was taken to enter data correctly. Data were double entered in order to assure accuracy. Original data were referred to in order to correct any discrepancies. All data were de-identified to assure anonymity and protect privacy of the women. Data were stored securely following the guidance of the University of North Carolina's School of Nursing privacy office. Only the principal investigator and research committee had access to the data.

Procedure Overview

IRB approval was obtained prior to the project's implementation. The retirement community does not have its own IRB or oversight board and accepted the IRB ruling from the University of North Carolina at Chapel Hill.

Logistical pilot. After IRB approval for the study was obtained, a three-day logistical pilot was completed prior to the initiation of the 8-week pilot study in order to identify real or potential logistical issues related to the web-based delivery of the intervention and data collection procedures. For this logistical testing, three women over the age of 65 were asked to use the website and data collection tools. No personal data were collected from these women, rather only information about the ease of use, clarity of the instructions of the data collection tools and website was elicited from each woman. Feedback from the women in the logistical pilot did not recommend changes to the website but some recommendations were made regarding the formatting of the questionnaires, such as font size and use of arrows for rating scales. After the 3-day logistical pilot finished and the recommended changes were made, recruitment of women began and the baseline meetings were initiated.

Baseline meetings. Two face to face baseline meetings with each participant occurred: one meeting at the beginning of the study prior to the intervention, a second meeting occurred 14-21 days after the first meeting and coincided with the intervention's start. Baseline data were collected at the initial meeting and repeated at the second meeting to explore changes in behavior that may have been related to increased awareness of continence behaviors.

Written informed consent was obtained at the first introductory meeting, Baseline Meeting 1, and the timeline of the study was explained. At this time, each woman completed baseline measures which consisted of the primary data collection questionnaire and GSE-UI. The baseline measurements were done with pen and paper and were completed during the first meeting with the primary researcher. Privacy was provided but the primary researcher was physically available to answer questions as needed. At the second introductory meeting, Baseline Meeting 2, the pen and paper questionnaires were again redistributed and completed in person. Also at the second meeting, a short, 15 minute, demonstration was given on how to access and use the website in order to review the bladder health education and complete the guided mindfulness practice. Each participant was encouraged to repeat demonstrate how to use the website and verbal reinforcement was provided where needed. The first three-day ICS bladder diary was distributed in paper form and instructions on how to complete it were given at the second meeting. For women who did not have access to the internet, one on one hands-on demonstration on how to use the CD for guided mindfulness was given, repeat demonstration and reinforcement was completed as needed, and a paper copy of brief bladder health education identical to the website content was provided. A log to record daily mindfulness practice throughout the intervention period was given to each participant in person at Baseline Meeting 2.

8-week intervention description. After the second individual baseline meeting, each woman began the 8-week intervention. Throughout the intervention period, technical support was provided via telephone, email, or in person. This support also included guidance and assistance for the participants as needed when they utilized the website or CD to carry out the intervention. The intervention period consisted of a review of bladder health education, completion of a three-day bladder diary at the beginning, middle and end of the intervention, and daily mindfulness practice. A time-line for the project is available in Appendix G.

Bladder health education. The women reviewed the educational material fully at least once within the first week of the study and returned to it as needed during the study.

Bladder diary. The ICS bladder diary was initially distributed during Baseline Meeting 2 and the women completed it over a 3-day consecutive period during the Intervention Week 1. This bladder diary was repeated three consecutive days during Intervention Week 5 and again for three consecutive days during Intervention Week 8. The second and third bladder diaries were delivered in person to participants during a three-day window at the end of Intervention Weeks 4 and 7. The bladder diaries were coded so that all data were anonymous. After completion of each three-day bladder diary period, the bladder diaries were collected from the women in person.

Mindfulness. The women completed and documented 10-15 minutes of mindfulness practice each day of the study. The first 14-days included specific, guided mindfulness practice delivered via the website or CD. The remaining six weeks the participants were free to use the mindfulness practice from the first 14 days, carry out their own mindfulness practice, or use the mindfulness resources provided in the website to carry out the mindfulness practice daily. The participants were asked to log daily how many minutes of mindfulness practice were completed

and if it was informal (unguided) or formal (guided). A bi-weekly telephone call to remind participants to complete the daily mindfulness practice and mindfulness log was made at the beginning of weeks 3, 5 and 7 with a three-day window before or after.

Post intervention debriefing session. After the 8-week intervention was complete, within a 10-day window, a final face to face individual meeting was held. At the final meeting, each participant was provided privacy to individually complete the same questionnaires used to collect baseline information. Additionally, each participant completed the feasibility survey. The final meeting also included a semi-structured interview and allowed for time for each participant to share her experiences. These experiences were transcribed during the meeting.

CHAPTER 5

DATA ANALYSIS

Results

Demographics. Ten participants were initially enrolled in the study. Two participants withdrew from the study. Eight participants successfully completed the study. Of the eight that completed the study, one woman had a history of urinary incontinence, but did not have objective evidence of current urinary incontinence at baseline, therefore data for this participant were not used to analyze efficacy and were only used to inform feasibility, therefore data from seven women were used for the efficacy analyses and data for eight were used for feasibility analyses.

The average age of the participants who completed the study was 82.75 (SD = 7.78), all identified as Caucasian, non-Hispanic females; all were post-menopausal; the average body mass index was 25.03 (SD = 2.514); seven women (88%) had between one and five pregnancies; none had history of cesarean sections. One woman reported no pregnancies (see Table1). Two participants who completed the study rated their health as fair at baseline, but changed their rating to good or excellent at post-intervention. Seventy-five percent (N=6) had experience with mindfulness practice, but none currently practiced mindfulness or had practiced it in the last six months.

TABLE 1. Baseline Characteristics of Study Participants

Characteristics	Sample Number (N=8)	Percent of Total
Age in years (mean ± SD)	82.75 ± 7.78 (69-93)	
BMI (mean ± SD)	25.03 ± 2.51 (21.3-28.3)	
Race		
Caucasian, non-Hispanic	8	100
Age Group		
≥ 65-69	1	12.5
≥ 70-74	0	0
≥ 75-79	2	25
≥ 80-84	1	12.5
≥ 85-89	2	25
≥ 90-94	2	25
Marital Status		
Married	2	25
Separated	1	12.5
Single (includes widowed)	5	62.5
Self-reported health		
Excellent/Good	6	75
Fair/Poor	2	25
Number of pregnancies		
0	1	12.5
1-5	7	87.5
Body Mass Index		
Normal (20-24.9)	4	50
Overweight (25-29.9)	4	50
Obese (30-39.9) [a]	0	0
Experience with Mindfulness Practice		
Yes	6	75
No	2	25
Currently practicing mindfulness[b]		
Yes	0	0
No	8	100

a – (AAFP, 2014)

b-Currently practicing was defined as practicing mindfulness more than 1x/week currently or within in the past 6 months.

Participation. Eighty-seven percent (7/8 participants) successfully completed: 1) the initial two weeks of guided mindfulness practice, 2) all three bladder diaries throughout the study, and 3) reviewed all the bladder health education at least once throughout the study. There was variation in how often participants completed the remaining six weeks of mindfulness practice (see Table 2). Two participants practiced 10-15 minutes of mindfulness three to five days per week for the remaining 6 weeks. Five participants completed at least 10 minutes of mindfulness practice five of seven days per week. One participant completed the bladder diaries, and bladder health education but felt like mindfulness was already incorporated into her regular life, so she did not actively participate in daily mindfulness practice as instructed via the website or CD.

Table 2. Mindfulness Completion for Each Participant (N = 8)

Participant	Did not practice mindfulness regularly	Mindfulness 3-5x/week	Mindfulness 5-7x/week
A		X	
B			X
C			X
D			X
E			X
F		X	
G	X		
H			X

Outcomes pertaining to research question one: efficacy. Seven women had urinary incontinence at baseline and were included in these analyses. The first research question was: Is an electronically-delivered self-management intervention that includes brief bladder health education, guided mindfulness practice, and a bladder diary effective in improving health related quality of life associated with urinary incontinence?

To answer this question, the women's scores on the pre and post validated questionnaires and bladder diaries were analyzed to assess improvement in the following outcomes: health related quality of life for urinary incontinence, as determined by responses to the ICIQ-FLUTS, frequency of daily voids, frequency of incontinent episodes and perceived self-efficacy of managing urinary incontinence.

The ICIQ-FLUTS measures the health-related quality of life impact of urinary incontinence. Particular attention was paid to the question: "On a scale of 0-10, 0 being not at all and 10 being a great deal, how much does leaking urine interfere with your everyday life?" There was a statistically significant difference in pre and post intervention scores on ICIQ-FLUTS health-related quality of life, see Table 2. Women's self-efficacy scores increased for four women and decreased for three women. Most women reported that incontinence had less effect on their lives during post-intervention semi-structured interviews. Table 2 provides a summary of the results for each outcome measure.

Bladder diary data. The average number of daily voids (regardless of continence status) from bladder diary one to bladder diary three decreased for four of seven (57%) participants. One participant did not experience change in the number of daily voids, and daily voids increased for two participants (see Figure 1). The average number of daily incontinent

episodes from bladder diary one to bladder diary three decreased for five of seven participants and did not change for two participants (see Figure 2).

TABLE 3. Bladder-related Outcomes Pertaining to Research Question One

Participant ID	Estimated Percentage daily mindfulness completed[a]	All (3) Bladder diaries completed[b]	Change in daily leakage urinary episodes from Bladder Diary 1 to Bladder Diary 3[c]	Geriatric Self Efficacy Scale Score change from Baseline 1 to Final[d]	Overall, how much does leaking urine interfere with your everyday life? (0 not at all and 10 a great deal).[e]	Subjective report of improvement (Y/N). "Do you think incontinence affects your life less now?"[f]
A	71%	100%	1.33 fewer episodes	8 points ↑	3	Y
C	88%	100%	2.67 fewer episodes	15 points ↓	5	Y
D	88%	100%	2 fewer episodes	23 points ↓	0	N
E	86%	100%	No change	51 points ↑	3	Y
F	71%	100%	No change	2 points ↑	4	Y
G	10%	100%	0.33 fewer episodes	2 points ↓	1	N
H	98%	100%	0.34 fewer episodes	47 point ↑	-1	Y
GROUP AVERAGE	73%	100%	0.95	9.7 point ↑	2.14*	5/7 Y 2/7 N

** = statistically significant ($p<0.05$)*

a- (Number of days mindfulness was completed) / (total days possible (48 days)) = percentage daily mindfulness completed

b- (Number of completed days of bladder diary) / (total days possible (9 days)) = percentage of completed bladder diaries

c- (Average number of daily leaks for bladder diary 3) – (average number of daily leaks for bladder diary 1) = change in daily leakage urinary episodes from bladder diary 1 to bladder diary 3.

d- (Total final GSE score) – (baseline 1 GSE score) = GSE score change from baseline 1 to final

e- (Final ranking for FLUTS question) – (baseline 1 ranking for FLUTS question) = change from baseline to final

f- Response at the final meeting to the question "Do you think incontinence affects your life less now?"

Figure 1: Baseline and Post-Intervention Three-day Daily Average Number of Voids (N=7)

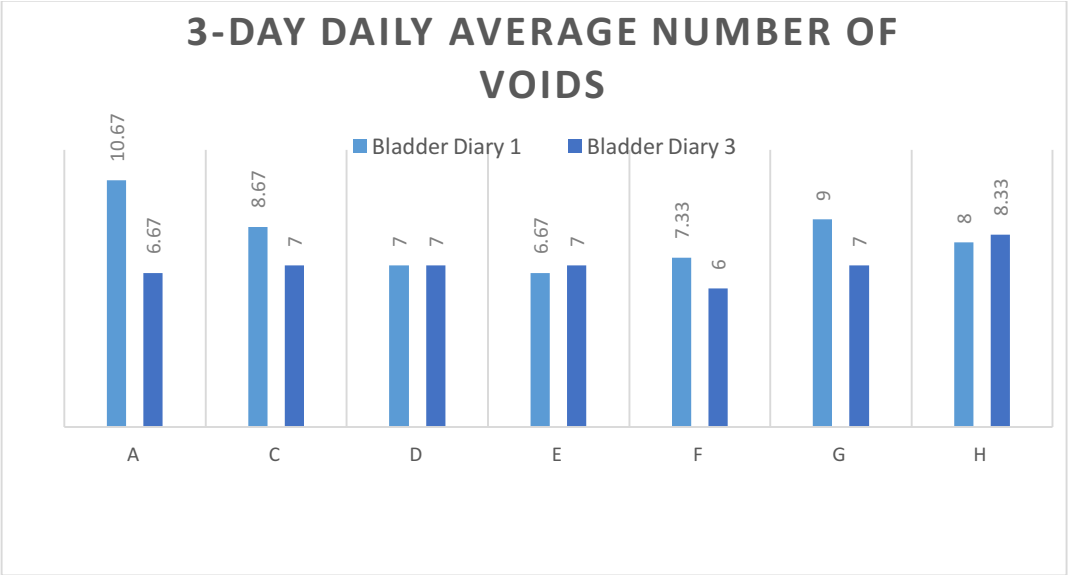
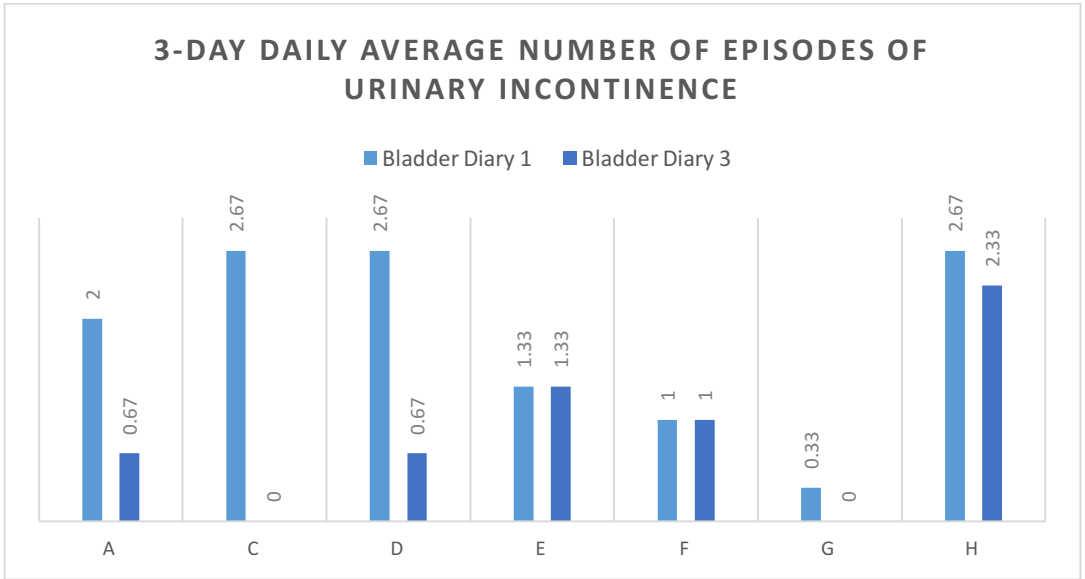
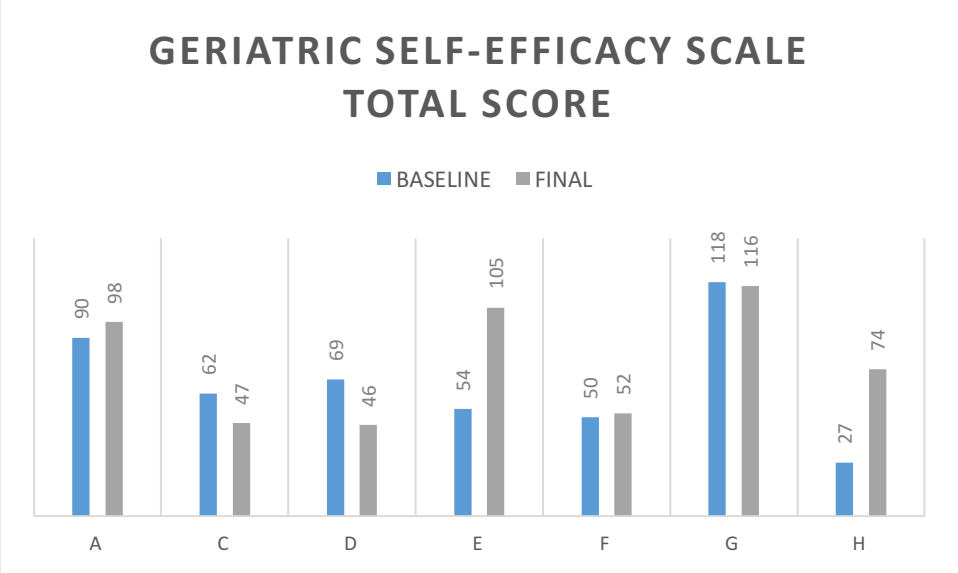


Figure 2. Baseline and Post-Intervention Three-day Daily Average Number of Incontinent Episodes (N=7)



Geriatric self-efficacy scale for urinary incontinence data. Four of seven participants had a higher total score on the geriatric self-efficacy scale and three had a total lower score (see Figure 3). No consistent patterns of improvement or worsening were identified for individual GSE-UI questions except for the questions pertaining to stress urinary incontinence, where all participants showed an increase in scores. Confidence in one's ability to hold urine while coughing was the only change that was statistically significant (p =0.046).

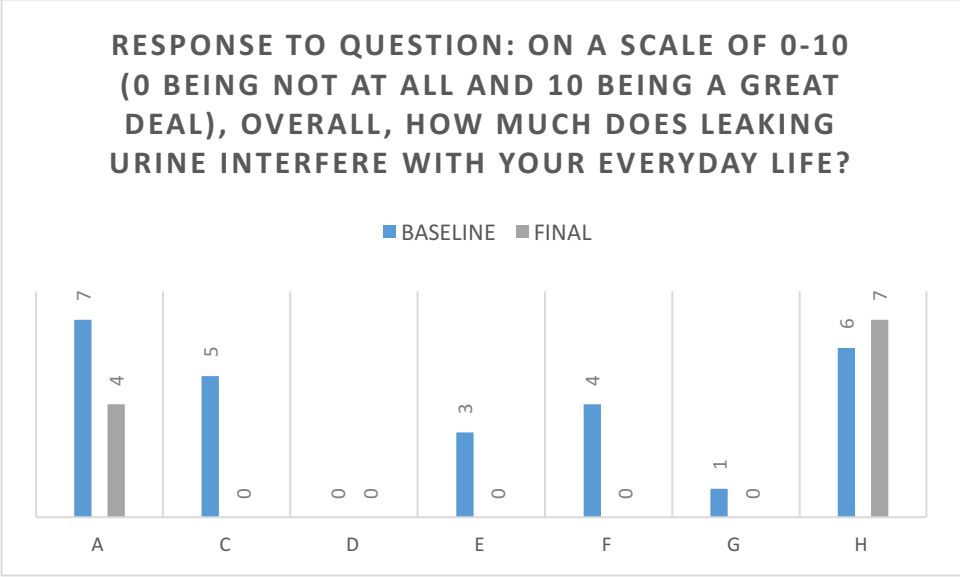
Figure 3. Baseline and Post-Intervention Geriatric Self-Efficacy Scale for Urinary Incontinence Total Score (N=7)



ICIQ-FLUTS Data. Five of seven participants had a decrease (lower rate of bother) in their ratings (0 being not at all and 10 being a great deal) of how much bladder leakage interferes with their everyday life, while one had no change and one had a minimal increase (see Figure 4). The group average was a statistically significant decrease of 2.14 (range = 1.57-3.71; p = 0.041). For the question: "How much does urine leaking before getting to the toilet bother you?" three participants had lower scores (decreased rates of bother), two had no change, and two had higher

score (increased rates of bother). Three other ICIQ-FLUTS questions pertained to dry overactive bladder symptoms. These were collected and analyzed, but not used to answer the research question as they did not directly address urinary incontinence. How much urinary frequency bothered the women decreased (decreased rate of bother) in three participants, increased (increased rate of bother) in two and did not change in two. No change was noted in how much nocturia bothered the individuals. Four women achieved decreased ratings in how much rushing to the toilet bothered them, one had no change and one had increased ratings.

Figure 4. ICIQ FLUTS Quantitative Scores of Bother (N = 7)



Post-intervention semi-structured interview data. Seventy-one percent of participants reported subjective improvement in bladder leakage in the post-intervention interview. Five of seven noted the mindfulness practice to be the most helpful aspect of the intervention with 60% of those noting that it was difficult to ascertain which part of the intervention was most helpful, but they pointed to mindfulness as the most likely cause as this was the most novel intervention pertaining to urinary incontinence (i.e., most had experience with bladder diaries and bladder

health education with little relief in the past). One woman noted the bladder diary being especially helpful while one woman noted the "whole experience" was most helpful. All of the women discussed that increased attention to and awareness of bladder symptoms helped them to achieve improvements.

TB-WEB data. The TB-WEB data were analyzed for changes in pre and post intervention toileting behaviors. The most frequently used behaviors both pre and post intervention (often/always) were emptying the bladder before leaving home (100%), emptying the bladder completely (100%) and sitting on the toilet to urinate when at home (100%) and in public (75%). The majority of toileting behaviors, including the most frequently used behaviors, assessed by the TB-WEB had little change post intervention. No significant change was noted in types or frequency of hygiene/absorbent products used (i.e. adult diapers, perineal pads, panty liners and protective underwear).

In summary, based on the data, this self-management intervention was effective in improving health related quality of life in the sample population. There was a significant decrease in the group average rate of bother for how much urinary incontinence interferes with everyday life. The majority of participants (71%) reported a subjective improvement in urinary incontinence, and 57% had improvement in perceived self-efficacy in managing incontinence. Though significance was not achieved, the majority of women (71%) did have a decrease in daily episodes of urinary leakage with no participants with increased episodes. The group average of daily incontinence episodes decreased by 0.95 episodes per day (range = 0.0-2.67).

Outcomes pertaining to research question two: feasibility. The second research question was: Is the intervention feasible for use in older women living independently in a retirement community setting?

Feasibility questionnaire. All 8 participants responded to the post intervention feasibility survey. This survey assessed the delivery method, specifically if it was user-friendly, the participants' perceptions toward the delivery method and if the participants would recommend the intervention and delivery method to other people with urinary incontinence and to their health care providers as part of urinary incontinence management. Feasibility scores were high with an average score greater than 8/10 in all areas (see Table 4).

Table 4. Post-intervention Feasibility Survey Results (N=8)

PARTICIPANT ID	The instructions were clear	The website (or CD) was easy to use.	The information provided on the website (or written) was easy to understand	Mindfulness resources on the website were useful.	The bladder diary was easy to use.	I would recommend the intervention to others with urinary incontinence.
A	10	10	10	10	10	10
B	10	10	10	10	10	10
C	10	9 (CD)	10	NA	9	10
D	10	5	8	8	9	9
E	10	8	10	7	8	10
F	9	7 (CD)	10	NA	10	10
G	10	10	10	7	10	10
H	10	8	9	10	9	10
Group Average	9.86	8.38	9.63	8.67 (n = 6)	9.38	9.86

Post-intervention semi-structured interview data. The semi-structured interview was used to assess each participants' experience with the study and gather qualitative data regarding each woman's individual experiences related to feasibility (N=8). In the post intervention interview, all eight participants answered "yes" that she would recommend the intervention to others. Three participants who used the Mind Over Bladder website (http://mindoverbladder-chaicore.vipapps.unc.edu) noted difficulties with using computers in general, causing barriers to using the website. Of those that that had difficulty with using the website, all reported that the

site itself had been easy to use, but that they had difficulty with accessing the site daily and with using external links from the site. Two participants, one who used the website and one who used the CD, thought that the music in the background while people were speaking made the guided mindfulness practice hard to follow. Three participants, one who used the CD and two who used the website, had difficulty with volume control and with not being able to hear the guided mindfulness well. None of the participants used the external links to mindfulness resources. Two participants used online external resources, but they found and accessed these resources on their own. Three participants exclusively used the guided mindfulness from the first 14 days to guide the entire study. Two participants used the guided mindfulness from the first 14 days and also completed self-guided mindfulness practice to complete the final six weeks. One participant used a combination of the 14-day guided mindfulness, external online resources, and self-guided mindfulness.

All but one participant found the introductory video to mindfulness to be helpful. One participant who did not find it helpful said that the introductory and guided videos were, "too slow," and she was not motivated to complete the mindfulness practice due to this. Several participants noted that they were "waiting" for the mindfulness practice to address the bladder directly and were apprehensive about how much this practice would help when the bladder was not being directly addressed through the mindfulness practice. The participants reported that these apprehensions eased as the study progressed.

An additional theme noted in the interviews was difficulty maintaining the motivation to complete daily mindfulness practice. Because of this difficulty with motivation, each participant found ways to tailor the intervention to her preferences to encourage motivation. Some did this

through using their preferred guided videos, others used self-guided practice, including mindful walking, mindful prayer and mindful listening, all activities that participants personally enjoyed.

In summary, the intervention was feasible for the participants. There were high scores on the feasibility survey and all the participants would recommend the intervention to other women with urinary incontinence and to their healthcare providers who help manage incontinence. Barriers were noted in the participant's own skills in using the internet, volume control, and motivation in completing the daily guided mindfulness practice.

Discussion

Data provided evidence that a self-management intervention including daily mindfulness practice, bladder health education, and bladder diaries was effective in improving health related quality of life associated with urinary incontinence in the participants. This is evidenced by a decrease in the majority of women's episodes of daily voids and daily incontinent episodes, increases in the GSE-UI total scores and a statistically significant change in the ICIQ-FLUTS question that measures how much bladder leakage affects everyday life. The majority of women (71%) also reported subjective improvement in their urinary incontinence symptoms. Because this was a pilot study with a small sample, limited parametric testing was performed. Changes were noted however in most outcomes and the intervention was well-received by the women.

Qualitative information from the interviews indicated women thought that mindfulness practice was the most important aspect of the self-management strategy in achieving improvements. For most of the women, mindfulness was a novel approach to bladder management whereas they had previously used bladder health education and bladder diaries without the positive effects they reported in this study. The efficacy of a multi-component intervention that addresses the neural circuits, or brain-bladder connection, is supported by a

2015 neuroimaging study by Smith, Kuchel & Griffiths. This study showed that damage to both structural and functional neural circuit connections in the brain that mediate voiding increases with age and is associated with severity of symptoms, thus bladder management strategies that address these neural abnormalities in addition to other therapies may be more effective than any single component therapy that focuses on the bladder (Smith et al., 2015). The women indicated that the mindfulness practice encouraged them to relax and listen to their bodies, which they surmised fostered increased awareness that in turn improved bladder symptoms. It is important to note that while most women pointed to mindfulness as being most helpful first, at least two felt that the "whole intervention" was helpful and neither could tease out which part was most helpful. Future research should explore which aspect of the self-management strategy can be most attributed for achieving improvement.

The intervention is potentially feasible in older adult women living independently in a retirement community setting as evidenced by high scores on the feasibility surveys, all women reporting that they would recommend the study to others and through overall positive experiences based on the post-intervention interviews. Generalizing the feasibility should be done cautiously because of the small sample size, homogeneity of living location, and lack of diversity in the sample population. Based on the semi-structured interviews, recommendations for changes to the website include adjusting volume settings and offering guided mindfulness that does not have music playing in the background when people are speaking. It is also important to consider an individual's proficiency in using computers, smart phones or tablets and/or her ability to use a CD player, as the largest barrier identified by the women who participated in this study was the women's own challenges with using technology.

Another common barrier noted was motivation to complete the daily mindfulness practice. This intervention had no built-in motivational tools or reminders other than regular follow-up with the research team. Providing motivation or reminders within the website may help to improve this. This could include text messages to remind participants to complete their daily mindfulness and making video clips of women at similar ages talking about the benefits of mindfulness available on the website.

Of particular interest was the concordance between the objective and subjective data gained from the study. Table 3 on p. 29 provides a summary of the objective and subjective data. Three participants had subjective and objective data that correlated. Objective and subjective data did not coincide in two participants who had no change in the number of episodes of urinary incontinence, but did have improvement in ICIQ-FLUTS scores, the GSE-UI scale, and subjective perception of improvement. Psychological factors and the role of self-efficacy have been found to greatly influence urinary incontinence management and may provide insight into this discordance (Tannebaum et al., 2008). Women's perceived ability to manage their symptoms (shown through an increase in the GSE-UI scores) could provide subjective improvement (evidenced by ICIQ-FLUTS and subjective reports of improvement) while not seeing objective changes. Two other participants had improvement in objective measures and perceived their symptoms were better in the interview, but their GSE-UI scales were worse. Why this occurred is worth looking into further and evaluating if these findings are consistent in future studies. Previous studies that sought to validate the GSE-UI did find correlation with women's symptom improvement and increased scores on the GSE-UI (Tannebaum, 2009), pointing to the conclusion that the two women who did not have correlation in this study are possibly atypical.

Another possible explanation is that the intervention itself brought heightened awareness to the problem and thus increased perception of the problem's role in the individual's life.

Another notable finding was improvement in ICIQ-FLUTS scores for questions pertaining to not only urinary incontinence but also dry overactive bladder symptoms, including frequency, nocturia and urgency. The majority of women had improvements in all areas and consistency was found across the ICIQ-FLUTS, so women who had improvements or worsening in one area tended to also note respective improvements or worsening in other areas. This indicates that mindfulness may also provide benefit for women who suffer from overactive bladder, not just urinary incontinence. While this intervention focused on the effects of mindfulness practice on urinary incontinence and not other symptoms of overactive bladder, other studies that have evaluated neural components of the cognitive response to bladder fullness have evaluated both urinary incontinence and overactive bladder (Tadic et al., 2012; Smith et al., 2015). This indicates that mindfulness may also address the neural components contributing to overactive bladder and not just urinary incontinence. Therefore, future research should explore the effects of this intervention on other lower urinary tract symptoms in older women.

Strengths and limitations. One strength of the study is that despite a small sample size, robust quantitative and qualitative data were collected from each of the participants, providing detailed information about the women's bladder habits and experiences with the study, which will be valuable to improve the intervention for future studies or to provide guidance in tailoring the strategy for clinical practice. Additionally, the self-management strategy provides a standardized format, making replication or expansion of the study feasible for future clinical or research practice. Finally, this study was carried out by women in their home environment without significant structure. The women were allowed to complete the components of the

intervention in their own homes, on their own time and could tailor the mindfulness practice to their needs. General guidelines were followed, but specific structure was not present. This may allow the findings to be more generalizable to real life situations and thus more applicable to clinical practice.

One limitation is the lack of control groups to provide evidence as to which aspect of the intervention is most helpful or if the summative strategy yields greater improvements than its individual parts. Comparisons from this study to other studies using the individual components is one way to better evaluate this, but due to the sample size, significance from this study in comparison to others must be applied cautiously.

CHAPTER 6

FUTURE CLINICAL AND RESEARCH IMPLICATIONS AND RECOMMENDATIONS

Clinical Practice Implications and Recommendations

This intervention can provide older women with an easily accessible self-management program that significantly improves urinary incontinence and perceived ability to manage urinary tract symptoms. It should be explored further in a larger and more diverse population, but is promising to be used to improve clinical care of women with urinary incontinence. Healthcare providers may be able to recommend this to patients and women can use it on their own to improve their symptoms. If the intervention could be developed further to be available via a public website or mobile application, this would allow for increased accessibility and ease of use. A mobile application may help to address one difficulty participants had, which was accessing the website at each visit. A mobile application would allow for the participants to simply click on a button from their device to bring up the guided self-management intervention, rather than having to plug in a web address or rely on a favorites list each time the site is accessed. Mobile applications may also be more user friendly, especially on mobile devices.

This innovative intervention yielded promising results and no noted adverse side effects. These data, combined with other literature supporting mindfulness as a management strategy for urinary incontinence, may encourage clinical practitioners to recommend this multi-component intervention to patients. This could be done through providing patients with a public website similar to the one used in this study, or through providing in-office education on bladder health,

providing bladder diaries for patients to complete and then recommending mindfulness resources as guides for the patient or connecting the patient to mindfulness classes or seminars in the community. A key difference between this and previous studies (Baker et al., 2012; Baker et al., 2014) is the labor intensity of the mindfulness practice. Previous studies have relied on face to face meetings in addition to at home practice, so if benefits can be achieved with the flexibility afforded by an online or multimedia delivered intervention, this may easier for patients' adherence.

A second implication is the further development of the website or mobile application that may be offered publicly, thus allowing this intervention to be recommended by clinical care providers without having to offer any aspects of the intervention on his or her own. Adjustments to the site should be made based on the women's feedback, including volume adjustment and creating a larger variety of guided practice that is organized into groups that will give the participant an idea as to the focus of the mindfulness and if it includes music and speaking or just speaking, as this was noted to be problematic for some women. Additionally, motivational tips and tools should be included in the website or mobile application in order to help women with the barrier of staying motivated to complete daily mindfulness practice.

When using this self-management strategy, patient characteristics and comfort level with computers or electronic devices must be considered and should be assessed when recommending these self-management strategies to patients or in future research. Additionally, it is important to allow flexibility for the patient to tailor the intervention to meet her needs, such as participating in mindfulness in a group setting versus individual if desired or through providing a variety of mindfulness resources so that the individual can find several that are most helpful to her.

Community stakeholders, especially providers who care for patients with urinary incontinence (i.e. specialists in pelvic health and gynecology and primary care providers who care for a large number of women and older adults) should receive education on this self-management program in order to encourage adoption of the intervention into their practices.

Creating a mobile application or website that is accessible publicly will allow the intervention to be easily used and thus more sustainable as it will be more likely for providers to recommend it if it is less of a time and effort burden on their part.

Research Implications and Recommendations

A significant research implication is that the findings from this study support the need for increased understanding of the brain-bladder connection. Future research should focus on how to better address the brain bladder connection and specifically how mindfulness can be used to better manage urinary incontinence and overactive bladder.

Future areas for research include evaluating this self-management strategy in a larger, more diverse group. A second recommendation for future research is to include control groups to assess the efficacy of the summative strategy versus its individual parts and to determine what mindfulness dose (daily minutes and how many times per week) is needed to achieve improvement in urinary incontinence.

CHAPTER 7

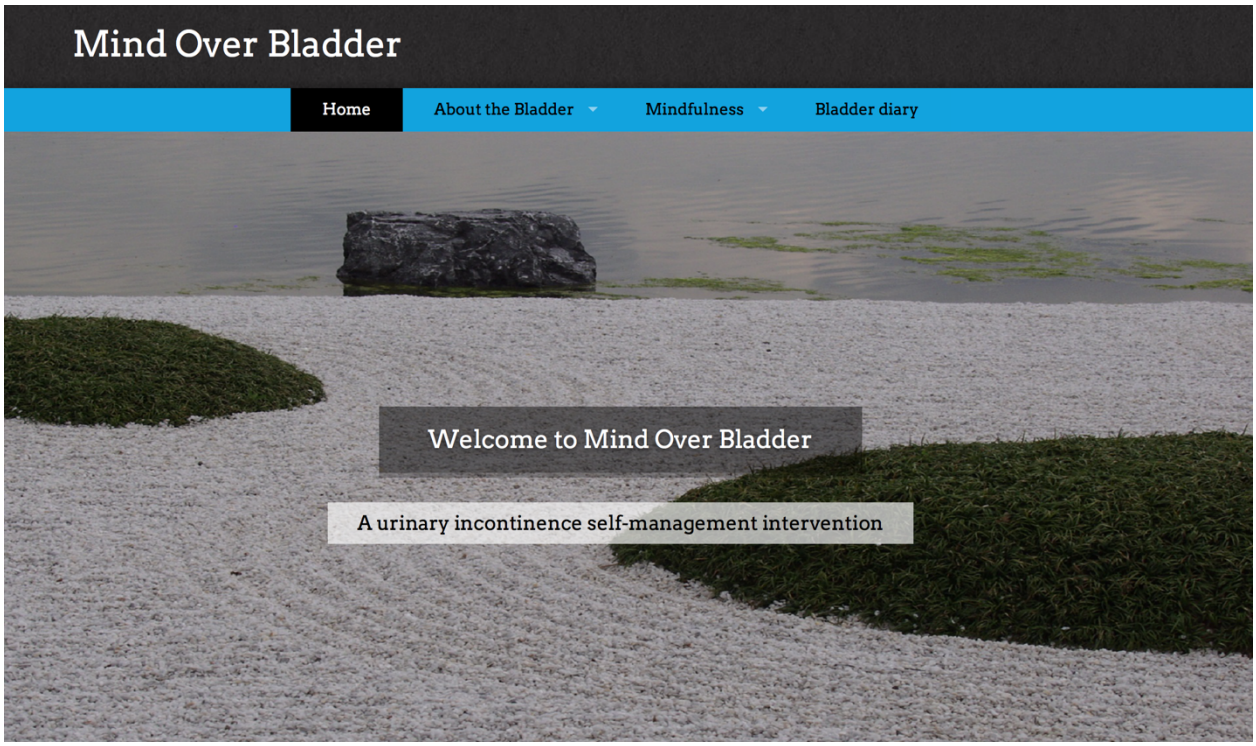
SUMMARY

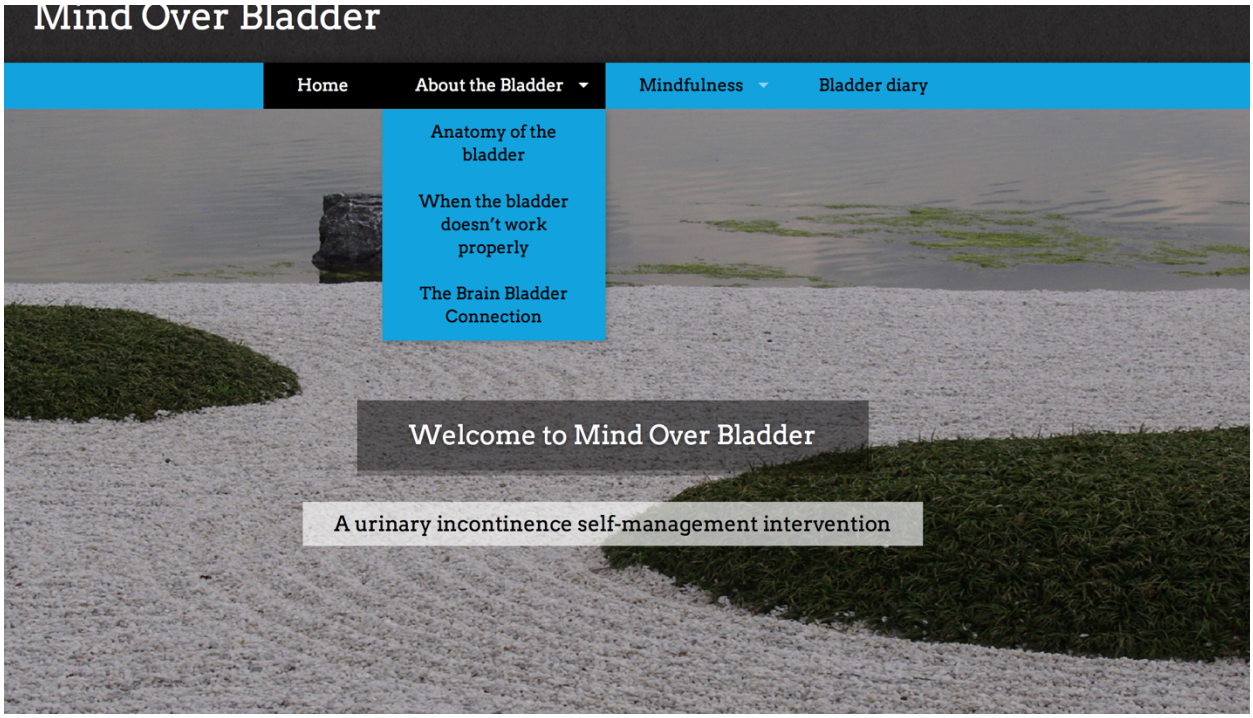
Conclusion

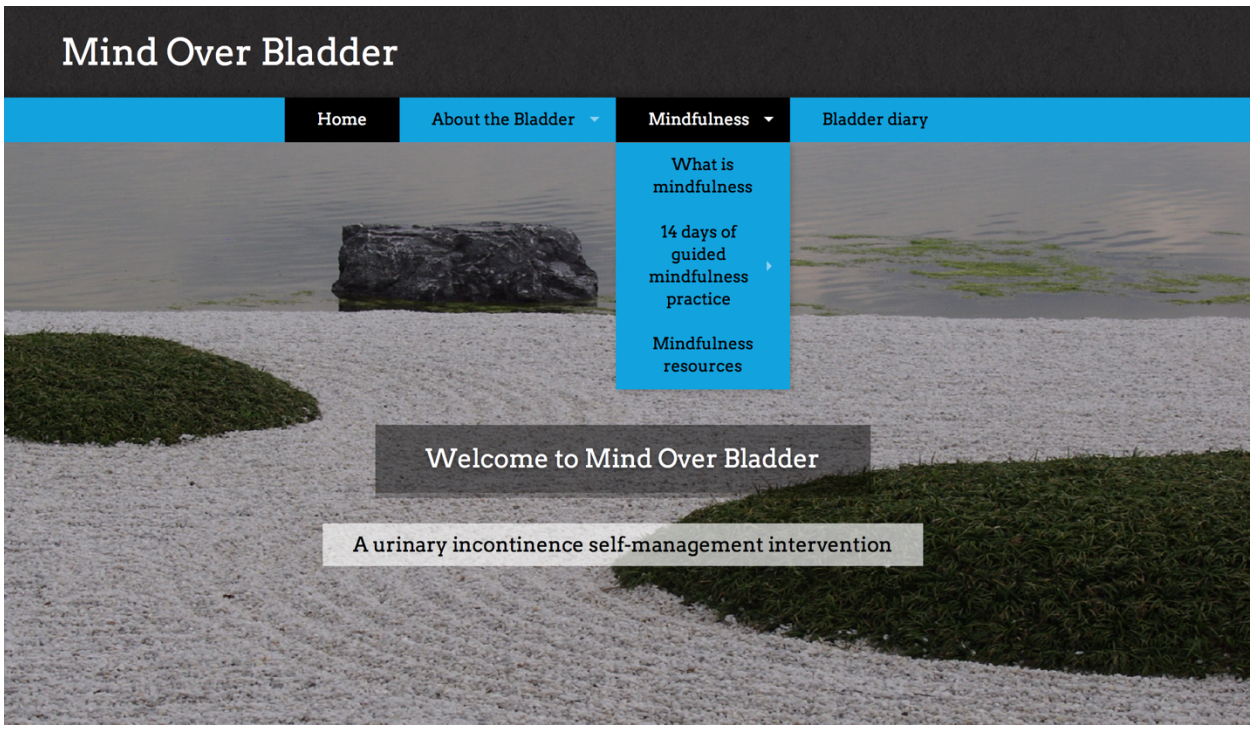
An innovative, electronically delivered self-management program including basic bladder health education, daily mindfulness practice and completion of sequential bladder diaries is promising as an effective and feasible strategy for improving frequency of urinary incontinence episodes and ability of an individual to manage urinary incontinence in older women who live independently in a retirement community. Frequency of daily bladder leakage decreased for the majority of participants and the group average rating scale score for, "how much incontinence affects your everyday life," had a significant decrease. High feasibility scores were noted in this sample population.

Further research with larger and more diverse sample sizes are needed. Clinical implications include the adoption of mindfulness, bladder diaries and bladder health education by clinical practitioners and development of a website or mobile application that is available publicly to deliver a standard intervention similar to the one offered in this study.

APPENDIX A: SCREENSHOTS FROM MIND OVER BLADDER WEBSITE







Mind Over Bladder

This page will guide you through a urinary incontinence self-management intervention. This website is separated into three sections: "About the bladder," "Mindfulness," and "The bladder diary." Please take some time to review each section and become familiar with the site. After you are familiar with how the site works, begin using the site to guide you through the 8-week "Mind Over Bladder" self-management intervention.

About the bladder

Gives a brief introduction to how the bladder works, bladder problems and the brain-bladder connection.

Mindfulness

explains what mindfulness practice is and how to practice it. It also includes 14 days of guided mindfulness practice. You should follow these guided mindfulness practice activities for the first 14 days. After the first 14 days you can repeat any of

The bladder diary

is the third part and explains what the bladder diary is and has a link to the International Continence Society's bladder diary. You should keep a three-day bladder diary at the beginning, middle and end of the 8 weeks (at the beginning of

APPENDIX B: PRIMARY DATA COLLECTION QUESTIONNAIRE

Directions: We are interested in learning from WOMEN about how women empty their bladders so we can better help women have good bladder health. This questionnaire should take about 20 minutes to complete. Please answer all items to the best of your ability. There are no right or wrong answers.
Please fill in the blank with your information or circle the response that best matches you.

What is your age?	_____years
Ethnicity: Do you consider yourself **Hispanic or Latino?**	0=no, 1= yes
Race: What race do you consider yourself to be? Select one or more of the following:	0 White, not Hispanic 1 African American or Black, not Hispanic 2 Asian 3 Native Hawaiian or other Pacific Islander 4 American Indian or Alaska Native 5 Other (specify) Write responses here: _____ _____ 6 Not Sure/Don't know 7 Do not want to respond
What is your marital status?	0 Married 1 Separated, divorced or widowed 2 Single never married
How would you rate your health?	0 Poor 1 Fair 2 Good 3 Excellent
How many pregnancies have you had?	0 1-5 More than 5
If you checked 0 (none) then skip the next 3 items	
How many live births have you had?	0 1-5 More than 5
How many vaginal deliveries have you had?	0 1-5 More than 5
How many caesarean deliveries have you had?	0 1-5 More than 5

Are you postmenopausal (you have gone 12 months or more without a menstrual period)?	0 = no 1 = yes 2 = unsure
What is your weight?	_____pounds
What is your height?	_____feet _____ inches

Experience with mindfulness questions:

Do you have experience with mindfulness practice?

Have your participated in a mindfulness-based class or seminar before?

Do you practice mindfulness regularly, and if so, about how many hours/week do you practice mindfulness?

Many people leak urine some of the time. We are trying to find out how many people leak urine and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

During the last month, how often have you leaked or lost control of your urine?	0 never 1 about once a week or less often 2 two or three times a week 3 about once a day 4 several times a day 5 all the time
We would like to know how much urine <u>you think</u> leaks. During the last month, how much do you <u>usually</u> leak (whether you wear protection or not)?	0 none 1 a small amount 2 a moderate amount 3 a large amount
Overall, how much does leaking urine interfere with your everyday life? Please circle a number between **0** (not at all) and **10** (a great deal).	0 1 2 3 4 5 6 7 8 9 10 not at all a great deal

During the last month, when does urine leak? (Choose all that apply to you)	0 Never - urine does not leak 1 leaks before I can get to the toilet. 2 leaks when I cough or sneeze 3 leaks when I am asleep. 4 leaks when I am physically active/exercising 5 leaks after a sudden strong desire to pass urine which is difficult to delay 6 leaks with washing my hands, or when I hear the running water. 7 leaks when I am opening or unlocking the door 8 leaks for no obvious reason. 9 leaks all the time
How many times do you urinate during the day?	0 1 to 6 times 1 7 to 8 times 2 9 to 10 times 3 11 to 12 times 4 13 or more times
How much does this bother you? (Please circle a number between **0** (not at all) and **10** (a great deal)	0 1 2 3 4 5 6 7 8 9 10 not at all a great deal
During the night, how many times do you have to get up to urinate, on average?	0 none 1 one 2 two 3 three 4 four or more
How much does this bother you? (Please circle a number between **0** (not at all) and **10** (a great deal)	0 1 2 3 4 5 6 7 8 9 10 not at all a great deal
Do you have to rush to the toilet to urinate?	0 never 1 occasionally 2 sometimes 3 most of the time 4 all of the time
How much does this bother you? (Please circle a number between **0** (not at all) and **10** (a great deal)	0 1 2 3 4 5 6 7 8 9 10 not at all a great deal
Does urine leak before you get to the toilet?	0 never 1 occasionally 2 sometimes 3 most of the time 4 all of the time

How much does this bother you? (Please circle a number between **0** (not at all) and **10** (a great deal)	0 1 2 3 4 5 6 7 8 9 10 not at all a great deal

Directions: How often do you use the following absorbent products in case of urine leakage?

Adult diapers (attaches on both sides of body) 	Never Rarely Sometimes Often Always 0 1 2 3 4
Protective underwear (like pull-ups) 	Never Rarely Sometimes Often Always 0 1 2 3 4
Perineal pads 	Never Rarely Sometimes Often Always 0 1 2 3 4
Panty liner 	Never Rarely Sometimes Often Always 0 1 2 3 4

	Never	Rarely	Some-times	Often	Alwa-ys
When I use public toilets, I worry about how clean they are.	☐	☐	☐	☐	☐
I try to avoid using public toilets.	☐	☐	☐	☐	☐
I try to empty my bladder before leaving my home.	☐	☐	☐	☐	☐
When I am away from my home, I try to hold my urine until I get home.	☐	☐	☐	☐	☐
When I am at my home, I empty my bladder even when I do not feel the need to urinate.	☐	☐	☐	☐	☐
When I am away from my home, I empty my bladder even when I do not feel the need to urinate.	☐	☐	☐	☐	☐
When I am at someone else's (family, friend) home, I empty my bladder even when I do not feel the need to urinate.	☐	☐	☐	☐	☐
When I am in a public place (stores, work, restaurant), I empty my bladder even when I do not feel the need to urinate.	☐	☐	☐	☐	☐
I empty my bladder without feeling a need to urinate, but do so "just in case".	☐	☐	☐	☐	☐
I will delay emptying my bladder when I am busy.	☐	☐	☐	☐	☐
I wait to empty my bladder until I feel I cannot hold my urine any longer.	☐	☐	☐	☐	☐
I wait too long (strong need to urinate or actual leakage) when I have to empty my bladder at work.	☐	☐	☐	☐	☐
I do not intentionally empty my bladder completely when I urinate.	☐	☐	☐	☐	☐
I push down (strain/tighten my abdominal muscles) to begin urinating.	☐	☐	☐	☐	☐
I push down (strain/ tighten my abdominal muscles) to keep the urine flowing during the urinating process.	☐	☐	☐	☐	☐
I push down (strain/ tighten my abdominal muscles) in order to empty my bladder.	☐	☐	☐	☐	☐

I push down (strain/tighten my abdominal muscles) to make the bladder empty faster.	☐	☐	☐	☐	☐
I empty my bladder completely when I urinate.	☐	☐	☐	☐	☐

The following statements describe various attitudes and behaviors women use to empty their bladders. Please select the response that best matches your feelings or behaviors when you empty your bladder.

At **HOME**, how often do you **URINATE** in the following positions? Please circle the response that best matches you.

I sit on the toilet seat to urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4
I crouch (hover) over the toilet when I urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4
I squat on the toilet seat to urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4

I stand over the toilet with my legs on each side of the toilet bowl, knees bent, facing either toward or away from the toilet to urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4

AWAY FROM HOME, how often do you **URINATE** in the following positions? Please circle the response that best matches you.

I sit on the toilet seat to urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4
I crouch (hover) over the toilet when I urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4

I squat on the toilet seat to urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4
I stand over the toilet with my legs on each side of the toilet bowl, knees bent, facing either toward or away from the toilet to urinate. 	Never Rarely Sometimes Often Always 0 1 2 3 4

Thank you for completing this survey!
Please return the survey in the sealed envelop to the secure container where no one but you can access the forms.

APPENDIX C: GERIATRIC SELF-EFFICACY SCALE FOR URINARY INCONTINENCE

How confident are you that you can hold your urine	not ←----------→ very confident confident 0←----------5----------→10
When you are at home and have to go to the bathroom?	0 1 2 3 4 5 6 7 8 9 10
When you are away from home?	0 1 2 3 4 5 6 7 8 9 10
Long enough to get to the bathroom in time during the night?	0 1 2 3 4 5 6 7 8 9 10
For at least 20 minutes when you feel the urge?	0 1 2 3 4 5 6 7 8 9 10
When coughing?	0 1 2 3 4 5 6 7 8 9 10
When sneezing?	0 1 2 3 4 5 6 7 8 9 10
When laughing?	0 1 2 3 4 5 6 7 8 9 10
When you are nervous?	0 1 2 3 4 5 6 7 8 9 10
How confident are you that you can . . .	
Visit places where you may have difficulty locating the bathroom?	0 1 2 3 4 5 6 7 8 9 10
Go out on social outings without worrying about urine loss?	0 1 2 3 4 5 6 7 8 9 10
Prevent urine loss without relying on pads or protection when you are at home?	0 1 2 3 4 5 6 7 8 9 10
Prevent urine loss without relying on pads or protection when you are out?	0 1 2 3 4 5 6 7 8 9 10

Pts >65y/o, MCID=14 pts, correlates with QoL, UI status, Sn .75, Sp 78

Total Score: _____

APPENDIX D: PERMISSIONS TO USE QUESTIONNAIRES AND SCALES

Permission letter for ICIQ-FLUTS use received Feb. 19, 2016:

> Dear Joanna
>
> Many thanks for your enquiry regarding the ICIQ. I attach here a copy of a permission letter (please note conditions of use), the UK English ICIQ-FLUTS, along with a summary detailing its background, validation and use. I have also enclosed the ICIQ-UI Short Form publication along with a publication detailing the background to the ICIQ project.
>
> The ICIQ modules that have been fully validated are currently being used internationally in both clinical practice and research (as outcome measures in clinical trials, clinical assessment tools, etc). I have attached a table detailing the modular structure of the ICIQ with available and developmental modules displayed.
>
> We would be very grateful if you could inform us how use of the instrument is going and inform us of any results you may publish. Should you need any further info or additional modules, please get in touch.
>
> Best wishes
>
> Liz Wetherell
>
> on behalf of
> Dr. Nikki Cotterill PhD BSc(Hons) RN
> Honorary Research Associate, University of Bristol
> Specialist Clinical Outcomes Researcher, Bristol Urological Institute, Learning and Research
> Southmead Hospital
> Westbury-on-Trym
> Bristol, BS10 5NB, UK
> Tel: 0117 4147933

Email correspondence from Dr. Tannenbaum on Feb. 17, 2016:

> Hi Joanna,
>
> Sounds like a great project. You are lucky to have Mary as your supervisor. Please pass on my warm regards to her.
>
> I'm pleased to grant you permission to use the GSE-UI for your doctoral work.
>
> Good luck,
>
> Cara

Cara Tannenbaum, MD, MSc
Scientific Director | Directrice Scientifique
Institute of Gender and Health | Institut de la santé des femmes et des hommes
Canadian Institutes of Health Research (CIHR) | Instituts de recherche en santé du Canada (IRSC)

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February 7, 2017

Joanna Long
University of North Carolina at Chapel Hill
Chapel Hill 27599

Dear Joanna:

This letter is to confirm that I gave you permission to use the TB-WEB in your study, "*Mind Over Bladder: Women, Aging, and Bladder Health,*" prior to its initiation. At the same time I had also shared a questionnaire that I developed with you that included the TB-WEB, demographic, health, and other items with the purpose of distributing it to older women who gave informed consent to participate in your study.

Sincerely,

Mary H. Palmer, PhD, RN, FAAN, AGSF
Helen W. & Thomas L. Umphlet Distinguished Professor in Aging

APPENDIX E: POST-STUDY FEASIBILITY QUESTIONNAIRE

On a scale of 1-10, with 1 being strongly disagree and 10 being strongly agree:

The instructions were clear:

1 2 3 4 5 6 7 8 9 10

The website was easy to use:

1 2 3 4 5 6 7 8 9 10

The information provided on the website was easy to understand:

1 2 3 4 5 6 7 8 9 10

Mindfulness resources on the website were useful:

1 2 3 4 5 6 7 8 9 10

The bladder diary was easy to use:

1 2 3 4 5 6 7 8 9 10

I would recommend the website to others with urinary incontinence:

1 2 3 4 5 6 7 8 9 10

APPENDIX F: QUESTIONS TO GUIDE THE SEMI-STRUCTURED INTERVIEW

Did you complete all of the content: bladder health education, bladder diary and mindfulness?

What did you find most helpful about the intervention?

What information you find least helpful?

What barriers/problems did you encounter during the study?

Do you feel that incontinence affects your life less now? If so, what parts of this study do you think helped to reach this improvement?

Do you think mindfulness helped with bladder control?

Were you able to consistently practice mindfulness? If not, why not? If so, what encouraged your continued practice?

Did you use any resources in the website to help you continue to practice mindfulness after the first two weeks?

Have you participated in mindfulness practice before? How would you compare this experience with previous experiences?

Will you continue to use mindfulness practice after this study is over?

Did you find the website easy to use?

Did you experience technical difficulties?

How often did you experience technical difficulties?

Would you recommend mindfulness practice to others?

APPENDIX G: PROJECT TIMELINE

Study Week 1 (14-21 days between Study Week 1 and 3)	**Study Week 3** (Intervention Week 1)	**Study Week 4** (Intervention Week 2)	**Study Week 5** (Intervention Week 3)	**Study Week 6** (Intervention Week 4)	**Study Week 7** (Intervention Week 5)	**Study Week 8** (Intervention Week 6)	**Study Week 9** (Intervention Week 7)	**Study Week 10** (Intervention Week 8)	**Study Week 11**
	Intervention Week 1	Intervention Week 2	Intervention Week 3	Intervention Week 4	Intervention Week 5	Intervention Week 6	Intervention Week 7	Intervention Week 8	
Baseline Meeting 1	Baseline Meeting 2								Final Meeting
	Distribute bladder diary and reminder to complete at meeting		Biweekly telephone reminder beginning of week	Distribute bladder diary at end of week	Biweekly telephone reminder beginning of week		Biweekly telephone reminder beginning of week; Distribute bladder diary at end of week		
	Bladder Diary 1				Bladder Diary 2			Bladder Diary 3	
	Review bladder health education	Bladder health education as needed	Bladder health education as needed	Bladder health education as needed	Bladder health education as needed	Bladder health education as needed	Bladder health education as needed	Bladder health education as needed	
	Review mindfulness instructions; Guided-mindfulness	Guided Mindfulness	Self-chosen mindfulness	Self-chosen mindfulness	Self-chosen mindfulness	Self-chosen mindfulness	Self-chosen mindfulness	Self-chosen mindfulness	

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